

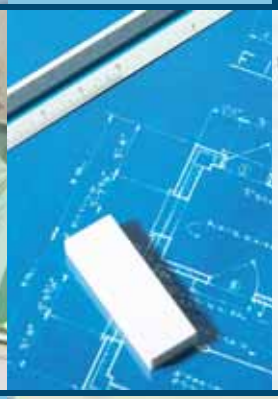

INTERNATIONAL EXPERT ADVISORY GROUP REPORT ON PALLIATIVE CARE

for Marymount Hospice and The Atlantic Philanthropies



CONTENTS

		Page No.
Chairman's Preface		**3**
Advisory Group Members		**4**
Executive Summary		**5**
Chapter 1	**Background**	**9**
1.1	Rationale for Establishment of the Advisory Group	10
1.2	Purpose of the Report	11
1.3	Terms of Reference	12
1.4	Meetings and Process Followed	13
1.5	Structure of Healthcare Services in Ireland and Current Reform	14
1.6	Healthcare Costs for Patients	14
Chapter 2	**Advisory Group Recommendations:**	
	Structure and Organisation of Palliative Care Services	**17**
2.1	Report of the National Advisory Committee on Palliative Care	18
2.2	Structure and Settings of Palliative Care Services	18
2.3	Accessing Specialist Palliative Care Services	20
2.4	Patients with Non-malignant Conditions	21
2.5	Inpatient Units	22
2.5.1	Admissions Policy	22
2.5.2	Security Issues	23
2.5.3	Religious and Spiritual Needs of Patients and Families	23
2.5.4	Smoking	23
2.6	Palliative Care in the Community	24
2.6.1	Primary Care	24
2.6.2	Specialist Palliative Care Teams in the Community	25
2.7	Palliative Care in Acute Hospitals	25
2.8	Seamless Delivery of Care	26
2.8.1	Integration	26
2.8.2	Key Workers	26
2.9	Financial Management Controls	27
Chapter 3	**Advisory Group Recommendations:**	
	General Design and Planning Considerations	**29**
3.1	Design Guidelines for Specialist Palliative Care Settings	30
3.2	General Design and Planning Considerations	30
3.2.1	Location/Site Selection	30
3.2.2	Internal Circulation Spaces	31

3.2.3 External Access 31
3.2.4 Infection Control 31
3.2.5 Use of Rooms 31
3.2.6 Mortuary Location 31
3.3 Structural/Functional Content 32
3.3.1 Size of Inpatient Specialist Palliative Care Unit 32
3.3.2 Single Bedrooms with WC and Shower Facilities 32
3.3.3 Artwork Storage Space 32
3.3.4 Isolation Room 32
3.3.5 Nurses Station 33
3.3.6 Religious and Spiritual Need 33
3.3.7 Contemplation Room 33
3.3.8 Facilities for Patients Wishing to Smoke 34
3.3.9 Facilities for Families and Children Visiting Specialist Palliative Care Units 34
3.3.10 Library & Resource Facilities for Patients and their Families 34
3.3.11 Other Resources and Facilities for Patients 34
3.3.12 Space for Community Specialist Palliative Care Services 34
3.3.13 Spiritual and Pastoral Care 35
3.3.14 Mortuary 35
3.3.15 Electronic Patient Records and I.T. Developments 35
3.3.16 Education and Training Department 36

Chapter 4 Education and Research 37
4.1 Importance of Education and Research 38
4.2 Education 38
4.2.1 Education of Healthcare Staff 38
4.2.2 Education of the Public 40
4.3 Research 40
4.3.1 Research Recommendations 40

Chapter 5 Benchmarks for Best Practice 43

References 52

CHAIRMAN'S PREFACE

Palliative care emerged during the 1960s as a response to the unmet needs of terminally ill patients and their families. For many years palliative care programmes remained mostly community based and with a strong clinical mandate. The sources of funding and administrative arrangements were quite variable from place to place. In most cases hospices and palliative care programmes occupied existing facilities and adapted their function to what was available rather than having the opportunity to conceive the physical space.

Limited integration with the established health care system and universities resulted in limited access to undergraduate and postgraduate education for physicians, nurses, and other health care professionals and very limited research efforts.

With the aforementioned limitations hospice and palliative care teams were outstandingly successful in bringing comfort to patients and families near the end of their life. This brought steady and continuous growth of clinical programmes and finally the complete acceptance of and efforts to integrate this discipline to the health care system.

Unfortunately, as programmes have grown and effort made in the integration of clinical services, education, research, and administration, standards for such programmes have been largely unavailable.

Standards are essential for the planning of new programmes, for the appropriate integration of different programmes existing within a region, and for the monitoring of the care and quality assurance. They provide a level playing field for the distribution of resources and workload, and they allow all participants in hospice and palliative care to speak a common language.

The extraordinary effort made by the committee from St. Patrick's Hospital (Cork) Ltd. with the support of the Atlantic Philanthropies is unique in the world. This team has assembled an international advisory group with the mandate to operationalise all aspects of the Irish national policy for palliative care as defined in the Report of the National Advisory Committee on Palliative Care.

The result is the most comprehensive set of standards of design and practice ever produced.

These standards pay extraordinary attention to detail. The comprehensive nature of the effort will result in major improvement in the care of terminally ill Irish patients and their families, the education of healthcare professionals, and the research contributions to the state of the art in palliative care.

This unique set of standards provides a template for many other countries and it will ultimately make a major contribution to the care of patients and families around the world.

Professor Eduardo Bruera

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EXECUTIVE SUMMARY

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CHAPTER 1

Background

In 2001 the Report of the National Advisory Committee (NAC) was published and was subsequently adopted by the Government as official policy for the development of palliative care services in Ireland. Design Guidelines for Specialist Palliative Care Settings were prepared by an expert committee in response to a recommendation in the NAC Report.

The Atlantic Philanthropies expressed a wish to assist the Department of Health and Children, both practically and financially, to accelerate the implementation of the NAC Report and to ensure that new developments would be based on best practice. An Advisory Group of international experts supported by The Atlantic Philanthropies was formed by St. Patrick's Hospital (Cork) Ltd. for this purpose. Marymount Hospice is an integral part of St. Patrick's Hospital (Cork) Ltd. and plans were already underway for a purpose-built replacement for Marymount Hospice. Terms of reference for the Group included making recommendations to inform those developing specialist palliative care (SPC) services and facilities, qualitative and quantitative standards, and financial management controls. This report details the recommendations of the Advisory Group and it should be considered in conjunction with the NAC Report[1] and the Design Guidelines for Specialist Palliative Care Settings[2].

CHAPTER 2

Advisory Group Recommendations: Structure and Organisation of Palliative Care Services

The Advisory Group endorses the Report of the National Advisory Committee on Palliative Care and urges implementation of the recommendations made therein at the earliest opportunity.

Access to SPC services should be on the basis of need and not based on diagnosis or life expectancy alone. *Specialist Palliative Care Services should be available to those individuals whose illness shows clear evidence of progression with increasing symptom severity, increasing complexity of care needed, and/or declining level of functioning, and of whom a specialist (e.g.*

cardiologist, respiratory physician, oncologist, etc…) could say "I would not be surprised if this patient died within the next year".

Palliative care services should have service agreements with, and be accountable to, statutory and voluntary agencies providing funding.

CHAPTER 3

Advisory Group Recommendations: General Design and Planning Considerations

The Advisory Group endorses the Design Guidelines for Specialist Palliative Care Settings and makes a number of additional recommendations in terms of operational policy and functional content. These include:

- Provision of single room accommodation for patients in inpatient units.
- Provision of adequate resource facilities for patients and families.
- Provision of adequate facilities for education.
- Anticipation of developments in information technology and adequate provision of space for computer hardware in clinical environments.

CHAPTER 4

Education and Research

The areas of education and research are cornerstones of best-practice palliative care and are believed by the Group to need urgent attention. Several recommendations are made in both of these areas. For education these include:

- The development of academic departments of palliative care are urgently needed in all medical faculties.
- Efficient and effective training of professionals to work in SPC is vital to overcome manpower issues. Planning for the future is of utmost importance to ensure that staffing needs are met.

- Basic principles of palliative care should be taught to healthcare professionals in relevant disciplines at both undergraduate and postgraduate levels.
- Education of policy makers, educational leaders, managers and the general public is also essential.

For research these include:

- Strong commitment to the development of palliative care research with core structures put in place at regional levels to support those undertaking research.
- Academic leadership to ensure focus on both clinical and health services research in palliative care.

CHAPTER 5

Benchmarks for Best Practice

Benchmarks for best practice palliative care delivery are recommended by the Group in the following areas:

- Service Availability/Access for patients with both malignant and non-malignant disease
- Standardised Patient Assessments
- Patient and Family Care
- Communication
- Educational Role
- Research Role
- Continuing Quality Improvement

These benchmarks will need regular review and updating. The recently formed National Council for Specialist Palliative Care would appear to be ideally placed to oversee implementation and updating of the benchmarks.

CHAPTER 1 BACKGROUND

1.1 RATIONALE FOR ESTABLISHMENT OF THE ADVISORY GROUP

The Atlantic Philanthropies are a group of Bermuda-based charitable foundations whose grant investments are focused internationally in four program fields: Ageing, Disadvantaged Children and Youth, Population Health, and Reconciliation and Human Rights. Improvement of palliative care services in Ireland has been identified by The Atlantic Philanthropies as a key element of its Ageing Programme.

In 1999, the Irish Minister for Health and Children established a National Advisory Committee (NAC) with a view to preparing a report on palliative care services in Ireland. The Committee's Report was completed in 2001[1] and was accepted by the Government as official policy for the development of palliative care services in Ireland. Design Guidelines for Specialist Palliative Care Settings[2] were prepared by an expert committee in response to a recommendation in the NAC Report.

The Atlantic Philanthropies expressed a wish to assist the Department of Health and Children, both practically and financially, to accelerate the implementation of the NAC Report and to ensure that new developments would be based on best practice. When The Atlantic Philanthropies expressed this interest several steps had already been taken to implement the NAC Report recommendations; however, much remained to be done. At the same time St. Patrick's Hospital had been working on plans for a new Specialist Palliative Care (SPC) inpatient unit to replace Marymount Hospice, which is an integral part of the Hospital. This project was likely to get substantial state support. Dr. Tony O'Brien (Consultant in Palliative Medicine) and Mr. Kevin O'Dwyer (Chief Executive Officer) of Marymount Hospice were actively involved in developing these plans for a purpose-built SPC unit adjacent to the existing Hospice. Dr. O'Brien had chaired the NAC and was a member of the expert committee involved in drawing up the Design Guidelines for Specialist Palliative Care Settings. The Atlantic Philanthropies decided to support St. Patrick's Hospital in undertaking further research to establish that their proposals were in line with current international best practice and that this would serve as a template for future planning and development of SPC units and services. It was decided to proceed by putting together a team of leading international experts in various aspects of palliative care service delivery and to include the expertise of a successful experienced Irish business-man.

1.2 PURPOSE OF THE REPORT

This report details the recommendations of the Advisory Group and it should be considered in conjunction with the NAC Report[1] and the Design Guidelines for Specialist Palliative Care Settings[2]. It is hoped that this report will be a useful resource to all individuals and groups interested in developing high quality specialist palliative care services both in Ireland and abroad.

The Advisory Group were asked to:

- Review background information and plans for the proposed new Marymount Hospice in Cork and to determine its suitability as a "best-practice" model for other hospice developments in Ireland.
- Establish benchmarks for "best-practice" palliative care services.
- Identify the appropriate elements of such services.
- Produce detailed implementation guidelines for each element.

Having regard to:

- The best interests of patients and families.
- Relevant national and international research and evidence-based data.
- The World Health Organisation definition of palliative care (2002).
- The report of the National Advisory Committee on Palliative Care (Ireland, 2001).
- The report of the Expert Group on Design Guidelines for Specialist Palliative Care Settings (Ireland, 2004).
- The Palliative Care Needs Assessments carried out by the Health Boards (Ireland, 2004).
- Information obtained following consultation with relevant persons and including site visits to established specialist units.

1.3 TERMS OF REFERENCE

The following terms of reference were drawn up for the Group:

To examine and evaluate current best practice and make recommendations that:

- Would serve to advise and inform those undertaking:
  - the establishment, management or further development of comprehensive regional palliative care services.
  - the upgrading, design and construction of comprehensive specialist palliative care facilities (including satellite units).
  - the provision or further development of palliative care facilities in non-specialist settings, such as acute or community hospitals.
- Would ensure that facilities design incorporate such features as would provide the highest possible standard of care environment, with due regard to the needs of patients, families, staff and volunteers.
- Would ensure that each specialist unit is capable of supporting and facilitating the delivery in its region of all aspects of a specialist palliative care programme, in all settings, including education, training and research.
- Would ensure, in any palliative care setting, a welcoming and calm environment, capable of offering full supportive care to the most seriously ill and dependent patient.

To produce, in the form of written best practice guidelines, the following outputs:

- The principles to be observed in the provision of a cost-effective, comprehensive, regional palliative care service.
- The range of services which should be provided.
- The qualitative and quantitative standards which should be set.
- The governance, management and staffing principles and norms which should be observed.

- The performance standards, indicators, reporting, audit and evaluation mechanisms which should be applied.
- The financial management controls, records and reports which should be implemented.
- The design, construction, operation, equipping and maintenance of inpatient, daycare, outpatient and regional base facilities, including education, research and regional support and "helpline" facilities.

1.4 MEETINGS AND PROCESS FOLLOWED

At the initial stages of the project, the Advisory Group members were furnished with the following documents:

- Draft Terms of Reference 23/6/04
- The Report of the National Advisory Committee on Palliative Care[1]
- A final draft copy of Design Guidelines for Specialist Palliative Care Settings[2]

The Advisory Group held the following meetings:

October 23rd 2004, New York

February 18th 2005, Dublin

In addition the Group communicated by teleconferencing and e-mails.

At the initial meeting the Group focused on the design of SPC settings with reference to the above reports. At the subsequent meeting outstanding design issues were clarified, and operational issues and benchmarks were discussed.

The Group agreed that site visits were not necessary for completing this report as almost all members of the Group had had the opportunity to visit several palliative care units in the course of their work and it was considered that further visits would be likely to add little to current expertise in this area.

1.5 STRUCTURE OF HEALTHCARE SERVICES IN IRELAND AND CURRENT REFORM

There are wide variations in the range and level of palliative care services available to patients in various regions of the country. SPC services in Ireland are primarily funded by statutory sources. In many cases, local organisations have service contracts with the local health board to provide palliative care services in a region. There is no national policy for reimbursement of services; this is done region by region.

At present a restructuring of the administrative bodies responsible for healthcare provision is taking place. For palliative care services the previous system of ten Health Boards has been reorganised into four geographical administrative areas (RHAs). Each of these areas has responsibility for a population of approximately 1,000,000 people. It is envisaged that there will be one oncology "super centre" in each region. The role of the Department of Health and Children will be to formulate and evaluate policy. The Health Services Executive (HSE) will become the largest single employer in the state and will have responsibility for the management, co-ordination and monitoring of the health service. The HSE will be organised on the basis of three service pillars: a National Hospitals Office, a Primary, Community and Continuing Care Directorate and a National Shared Service Centre. Initially in the NAC report it was envisaged that each of the health board regions would have a palliative care budget overseen by a development committee who would prioritise funding. In the reform process palliative care will be in the Primary, Community and Continuing Care pillar.[3,4]

There is a tradition of public generosity to "hospices" and palliative care services in Ireland. Local fundraising groups and charities currently play an important role in raising funds for both capital and ongoing costs.

1.6 HEALTHCARE COSTS FOR PATIENTS

Currently approximately one third of the population is entitled to a medical card. This allows provision of free healthcare (primary care, hospital care, medications). All people over 70 years of age have entitlement to a medical card and for all others it is means-tested. There is some discretion in the allocation of medical cards to individuals with serious life-limiting illnesses who are above the cut-off point for automatic medical card entitlement. For those who do not have medical cards a payment system exists for medical care:

- A general practitioner (GP) visit costs approx 40 - 50 Euro, house calls cost more. Most private healthcare insurance policies do not cover primary care (some cover a proportion of the cost above a certain threshold).

- Hospital charges: to attend accident or emergency or a public outpatient clinic without a GP referral, there is a cost of 55 Euro. For public inpatient care there is a cost of 55 Euro/day. The maximum amount one individual is liable for in hospital charges is 550 Euro in a year.[5] After this there is an entitlement to free hospital care as a public patient. Many people elect to pay private healthcare insurance. This covers most of the costs of acute hospital care.

- Medication costs: families are liable for the first 85 Euro spent per month on prescription drugs. There is a state scheme that covers costs of medication in excess of this.

GPs are paid on a capitation fee system for medical card patients registered with them. There is a national scheme whereby a once-off palliative care payment of 170 Euro (approx) may be given to GPs "for the provision of domiciliary care for the final phase of a terminal illness" for patients with a medical card. The granting of this fee is subject to budgetary constraints.

CHAPTER 2

ADVISORY GROUP RECOMMENDATIONS:

Structure and Organisation of Palliative Care Services

2.1 REPORT OF THE NATIONAL ADVISORY COMMITTEE ON PALLIATIVE CARE

The Advisory Group endorses the Report of the National Advisory Committee on Palliative Care and urges implementation of the recommendations made therein at the earliest opportunity. At the launch of the report in 2001, full implementation was expected by 2008 by the then Minister for Health and Children, Micheál Martin. The Group are concerned at the rate of progress in certain areas and would hope that implementation can be addressed in a comprehensive fashion.

The Group believes that implementation requires recognition that staffing levels recommended in the report represent minimum staffing levels.

Implementation of the report will require consideration of the new health structures in the country.

2.2 STRUCTURE AND SETTINGS OF PALLIATIVE CARE SERVICES

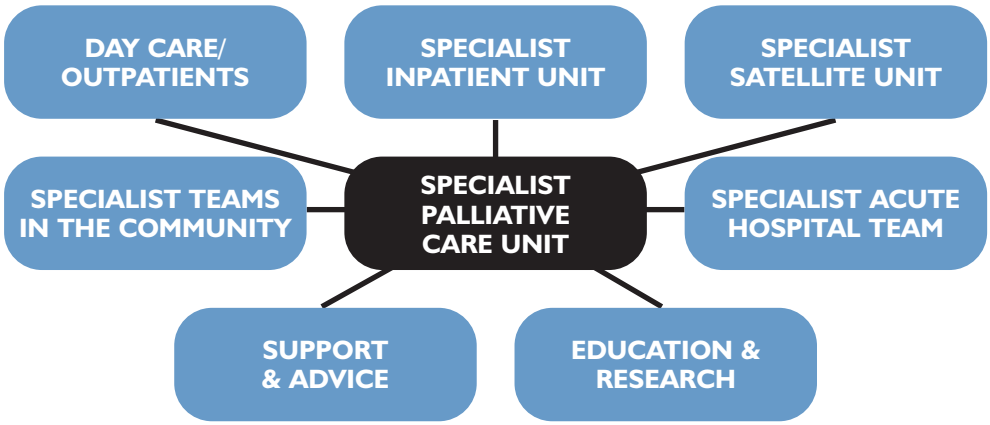


Figure 1: Components of a Specialist Palliative Care Service[1]

Both specialist and non-specialist palliative care are necessary in a variety of settings in order to provide a comprehensive, coherent palliative care service. The Report of the National Advisory Committee on Palliative Care made detailed recommendations in this regard, with the SPC unit (Figure 1) as the core element of the SPC service. It is essential that seamless movement of patients between settings of care and levels of expertise can take place depending on their needs (Figure 2). If any setting of care is lacking in resources or not functioning adequately in this framework, it impacts adversely on all others (e.g. access to intermediate level of care in community hospital/nursing home beds for those who are highly

dependant but symptom controlled are very important to ensure bed availability for those who need it in SPC inpatient units). Lack of bed availability in any of these settings will adversely affect transfer of patients to and from other settings.

Integrated regional palliative care programmes (including a SPC inpatient unit, continuing palliative care beds, family doctor reimbursement systems for palliative care and acute hospital nurse and physician consult teams) have been found in other countries to be cost-efficient, as many patients who are currently cared for in the more expensive acute hospital setting can be cared for in the less expensive settings of continuing care (community hospitals and nursing homes) and at home.[6,7] In addition, such programmes have been found to increase the numbers of patients accessing palliative care. Excellent standards of palliative care can be delivered in this way so long as settings of care are matched to patient and family need. In addition, patient care can often take place in their home or in locations closer to their home.

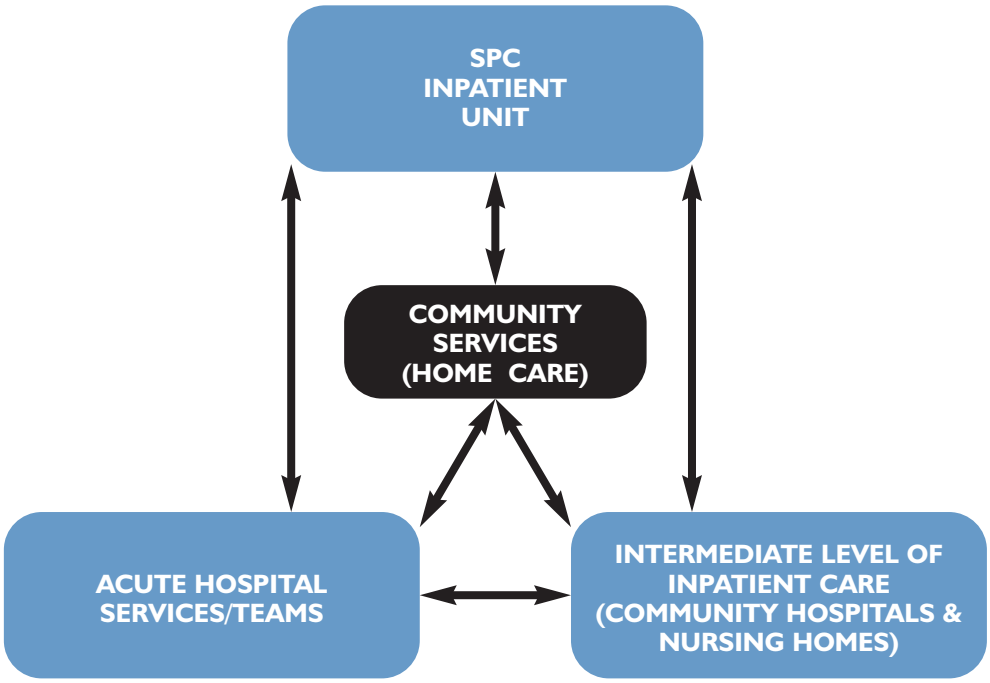


Figure 2: Settings where Patients Receive Specialist and Non-Specialist Palliative Care[1]

The current system in Ireland does not facilitate the flow of patients between settings of care. A patient is entitled to free care (above the annual threshold for hospital charges of 550 Euro) while in a SPC unit, but care in a nursing home will often incur considerable cost (despite the fact that some allowance towards nursing home cost may be available on the basis of financial need). The financial implications of this act as a barrier to the transfer of patients to nursing home care. In some smaller towns, community hospitals may be able to offer free inpatient care to palliative care patients, but this is variable and usually not available to patients in larger urban centres.

2.3 ACCESSING SPC SERVICES

Defining an appropriate entry point for patients to SPC services requires consideration of many variables. Access should be on the basis of need and not based on diagnosis or life expectancy alone. The Group considers that the following is an appropriate working definition for access to SPC services in Ireland:

Specialist Palliative Care Services should be available to those individuals whose illness shows clear evidence of progression with increasing symptom severity, increasing complexity of care needed, and/or declining level of functioning, and of whom a specialist (e.g. cardiologist, respiratory physician, oncologist etc…) could say "I would not be surprised if this patient died within the next year".

Patients fulfilling these criteria should have access to the full range of SPC services outlined in the Report of the National Advisory Committee on Palliative Care. Other individuals might on the basis of a specific need (e.g. chronic pain) access an aspect of the SPC service (e.g. consultant in palliative medicine for symptom control) for a limited time period, followed by discharge back to their referring doctor and re-referral at a future date if needed. This latter group of patients would not be eligible for the full range of SPC services unless at some stage they met the required criteria.

There is no internationally agreed figure for what is considered to be an appropriate proportion of cancer patients who die who access SPC. Approximately 60 - 70% of patients with advanced cancer have multiple symptoms. Multiple symptoms could be considered to be an indicator of likely need. In Edmonton over 80% of cancer patients who die access SPC through the regional palliative care programme at some stage.[6,8] In Catalonia this figure is approximately 70%.[9] If 70% access is applied to the number of cancer deaths in Ireland (Central Statistics Office figures report 7621 deaths from malignancies in 2002) approximately 5335 of these patients should be accessing SPC at some stage before death.

Estimates of numbers of patients with non-malignant diagnoses who might benefit from SPC services have been based on research performed in the UK.[10] It has been estimated that there are approximately 6,900 deaths/year in a population of 1,000,000 due to progressive non-malignant disease and of these one fifth would be expected to have symptom severity comparable to the top one third of cancer patients. Using these figures it has been extrapolated that at least 5,000 patients in Ireland annually would have a recognised period where they would be likely to benefit from SPC.

When considering access to SPC services it is important to ensure that:

- Those patients who access SPC are the ones who need it most.
- The flow of patients to and from various settings of SPC should be dictated by need.
- There should be a local strategy for improving access of non-cancer patients (stage 4 heart failure, renal failure, end stage COPD, etc…) to SPC services.

2.4 PATIENTS WITH NON-MALIGNANT CONDITIONS

As discussed above, access to palliative care services should be on the basis of need. This should apply to all settings of palliative care. Health authorities and agencies that fund palliative care services should ensure that services providers are providing appropriate services to patients with non-malignant conditions according to need. The provision of an adequate supply of inpatient care beds at an intermediate level is essential for the provision of satisfactory services in all settings to this patient population, as there may be a reluctance to admit these patients to SPC inpatient unit beds due to possible increased length of stay if transfer is not possible.

It is accepted that for many progressive non-malignant conditions the disease trajectory is less predictable than for patients with advanced malignancies, and that a monitoring process may be needed. Some non-malignant conditions have by nature an episodic component (e.g. COPD, CCF), whereas others are more obviously progressive (e.g. motor neuron disease). Symptoms and problems encountered by patients with non-malignant conditions may require very specific approaches, and it can be helpful to focus on these while simultaneously providing holistic care. The concept of symptom complexity, and matching this with stratified levels of intervention, is considered to be important in choosing appropriate settings for palliative care in these patients. Future research in this area should inform policies and practice.

Developing relationships between SPC staff and hospital doctors is vital in order to improve the access that this group has to SPC services. Education of healthcare staff is very helpful in raising the awareness of potential benefits of SPC input into management of patients with progressive non-malignant conditions.

2.5 INPATIENT UNITS

2.5.1 Admissions Policy

The following points were highlighted by the Group and should be taken into account when developing admissions policies for SPC inpatient units:

- For most patients optimal stabilisation of distress has been found to occur somewhere between 1 and 2 weeks after admission to a tertiary inpatient unit.[11]

- Matching the type of palliative care with an individual patient's and their family's needs should be kept in mind when considering admission policies for SPC inpatient units. Needs may change over time (e.g. a patient may require admission for management of uncontrolled symptoms; once these symptoms are controlled a transfer to a different setting of care, such as intermediate care in a community hospital or care in the community, may be more appropriate). It is important to keep in mind that most patients wish to be cared for at home. A recent survey commissioned by the Irish Hospice Foundation found that the preferred place of care if dying for 67% of the Irish public surveyed was their own home. Hospital and hospice care were each chosen by 10%.[12]

- When developing admission policies it is important to consider the psychological impact of moving a patient from high intensity care to a setting with lower intensity. Patients and families should at the time of admission be given information on the purposes that each setting serves, and advised regarding the possibility of discharge or transfer to other settings of care as appropriate.

- Admission policies must take into account the needs of patients with non-malignant diseases and the increasing awareness of the benefits of palliative care to these patients.

- It is important that emergency admissions can occur 7 days a week.

- It may be possible to offer patients different things depending on their needs e.g.:

    1. Therapeutic challenge (i.e. opioid switch, bisphosphonates, new sedation, changing aspects of nursing care, etc…). Such admissions could take 48 hours or less.
    2. Acute symptom control.
    3. Rehabilitation programmes.
    4. Carer confidence i.e. training informal carers to deliver the clinical care required.
    5. Carer respite.
    6. Care during the terminal phase.

2.5.2 Security Issues

The main reception area for SPC inpatient units should be staffed 7 days a week, 24 hours a day. A security procedure should also be put in place in order to identify patients and both informal and professional visitors to the unit.

2.5.3 Religious and Spiritual Needs of Patients and Families

Spiritual care is considered to be the responsibility of all staff and volunteers who, having identified a need, should either meet the expressed need themselves or refer patients on appropriately. Each SPC unit should have a qualified person(s) responsible for ensuring that these needs are assessed and addressed appropriately. The NICE Guidance[13] in the U.K recommends the appointment of spiritual care co-ordinators (either religious or lay) who can take on the needs of the wider community. There should be good communication between spiritual care providers within SPC services and those within the community, as well as those providing bereavement support.

2.5.4 Smoking

The right of staff to be protected from the risks of passive smoking in the work place is protected by law in Ireland.[14] It is acknowledged that this is a complex issue; on the other side are patients (most of whom have smoked for several years) who have very limited life expectancy and huge issues with which to deal. Whilst a national ban on smoking in the workplace has been introduced, "hospices" remain one of the few exempted areas. This exemption applies only to patients and only within designated smoking areas. The Group recommends that smoking should not be allowed in bedrooms, and designated rooms with enhanced ventilation systems should be provided for patients (not visitors) who wish to smoke. Patient may avail of these smoking facilities if they are physically able to access them independently and are not cognitively impaired to such an extent that there are safety issues if they smoke. Patients who cannot physically access smoking facilities independently may do so if they have a visitor who is willing to take them. Staff members should not be expected to take patients to smoking facilities or to supervise them while they smoke. Nicotine replacement in the form of patches, gum or inhalers should be made available for patients who are nicotine addicted and who cannot access smoking facilities. The situation with respect to smoking in "hospices" is likely to evolve over the coming years.

2.6 PALLIATIVE CARE IN THE COMMUNITY

The provision of high quality, well-resourced palliative care in the community is of utmost importance. Most palliative care in the community is carried out by general practitioners and public health nurses. Where a patient is referred to SPC in the community, it is recommended that this care is carried out by a community palliative care team, all members of which are trained in SPC.

2.6.1 Primary Care

In general, the integration of primary care services is sub-optimal in Ireland. There are no formal links between GPs and public health nurses (PHNs). Most GPs work from their own premises and PHNs work from health centres run by the health boards. It has been proposed that there will be a move towards the provision of primary care by multidisciplinary primary care teams and that liaison between primary and secondary care services will be improved.[15]

General Practitioners

The commitment of GPs is very important in the delivery of high quality palliative care to as many patients as possible. A number of barriers to GP involvement in palliative care service delivery have been highlighted by research[16]:

1. Lack of financial re-imbursement. The delivery of palliative care to patients can be time-consuming and uses resources.

2. The average GP only sees 1 to 3 palliative care patients/year, and because of this often lack experience and expertise. The support of a specialist is therefore very important.

3. Most GPs have never received formal education in palliative care. Busy schedules limit their availability to attend educational sessions; therefore opportunistic education (when a GP has a patient with a need) is desirable.

4. GPs need support services that work and healthcare professionals with whom they can work.

Public Health Nurses

There are approximately 2,000 registered public health nurses in Ireland delivering care to those who need it in a very diverse range of situations. PHNs provide palliative care to large numbers of patients in the community. It is recommended that a strategy to address the palliative care educational and training needs of PHNs be developed at national level.

2.6.2 Specialist Palliative Care Teams in the Community

At present there is considerable geographic variation in the structure of community palliative care teams in different regions of the country. Some are under a SPC service (consultant-led); others (often in regions where there is no SPC unit or consultant) are managed by the director of public health nursing. Currently most community palliative care teams consist of palliative care nurses only. These nurses (often single-handedly) have developed palliative care services. However, for services to develop nationally, the recommendations of the NAC report should be implemented: "the specialist palliative care team in the community should be an inter-disciplinary consultant-led team". The report (Chapters 5 and 8) outlines the range of disciplines and staffing levels that should ideally make up SPC teams in the community. Adequate levels of administrative staff are also vital to support these teams. There is a need to appoint more consultants in palliative medicine, particularly in regions where there are none, and to establish and develop multidisciplinary teams with specialist training.

Work Practices

It is essential that members of the SPC community team work closely with each other as part of an interdependent multidisciplinary team. The team should have a collective understanding of patients and it is vital that members do not work in isolation. There should be regular team meetings with a work planning, support and team-building focus. Team members should have day-to-day contact with other team members and reporting relationships should be fostered in order to prevent professional isolation.

2.7 PALLIATIVE CARE IN ACUTE HOSPITALS

Attention should be given to the development of operational links between the SPC inpatient unit and the acute hospital to facilitate seamless delivery of care (e.g. specialists to visit patients in SPC inpatient unit where possible and palliative medicine consultants to visit patients in acute hospitals). If patients attend acute hospitals (e.g. for treatment, investigations, outpatient clinics etc…) queuing should where possible be avoided.

The roles and structures of SPC teams in acute hospitals are described in detail in Chapter 7 of the NAC Report.[1] Their role is primarily one of support and advice for other healthcare professionals regarding management of patients in need of palliative care. This can be achieved in a number of ways, including consult services, joint ward rounds, joint outpatient clinics, and other educational activities.

Education of non-specialist palliative care staff is very important in the acute hospital setting to ensure that staff develop skills and knowledge appropriate for the management of palliative care patients, and don't become de-skilled by the presence of an SPC team (e.g. oncology junior doctors and nurses work in a SPC unit for a period to gain experience, SPC team take all opportunities to impart information and empower other colleagues). It should also be noted that staff can have difficulties in obtaining cover to attend formal training and educational sessions. Close links should be fostered between SPC teams in acute hospitals and the SPC unit.

2.8 SEAMLESS DELIVERY OF CARE

2.8.1 Integration

Good communication between healthcare providers is essential to ensure best-practice palliative care. The delivery of high quality palliative care requires involvement of many healthcare professionals in a variety of disciplines and specialities at community, acute hospital and inpatient service levels. Communication between these professionals and systems to allow streamlined movement of patients between different aspects of the service is vital. The Group believes that patient care would be enhanced by improved communication and co-ordination between health care professionals involved in an individual patient's care, and recommends that attention be given to this important detail of patient care. Improved awareness of the needs of patients is promoted by this attention to detail. Earlier referral and increased referral of patients to SPC services by GPs and hospital specialists is a potential consequence of this raised awareness. SPC services should support healthcare professionals at community and acute hospital level by disseminating information and educating and empowering others (e.g. public health nurse to reload syringe drivers).

2.8.2 Key Workers

The concept of adopting key workers in the community is felt to be a very important possibility that offers potential to improve integration and co-ordination of care. Key workers should act as part of a team and can be from any professional group. This concept has also been mentioned in the Primary Care Health Strategy as being appropriate for some patients.[13] The professional identity of the key worker can change over time according to the needs of the patient and/or their family.

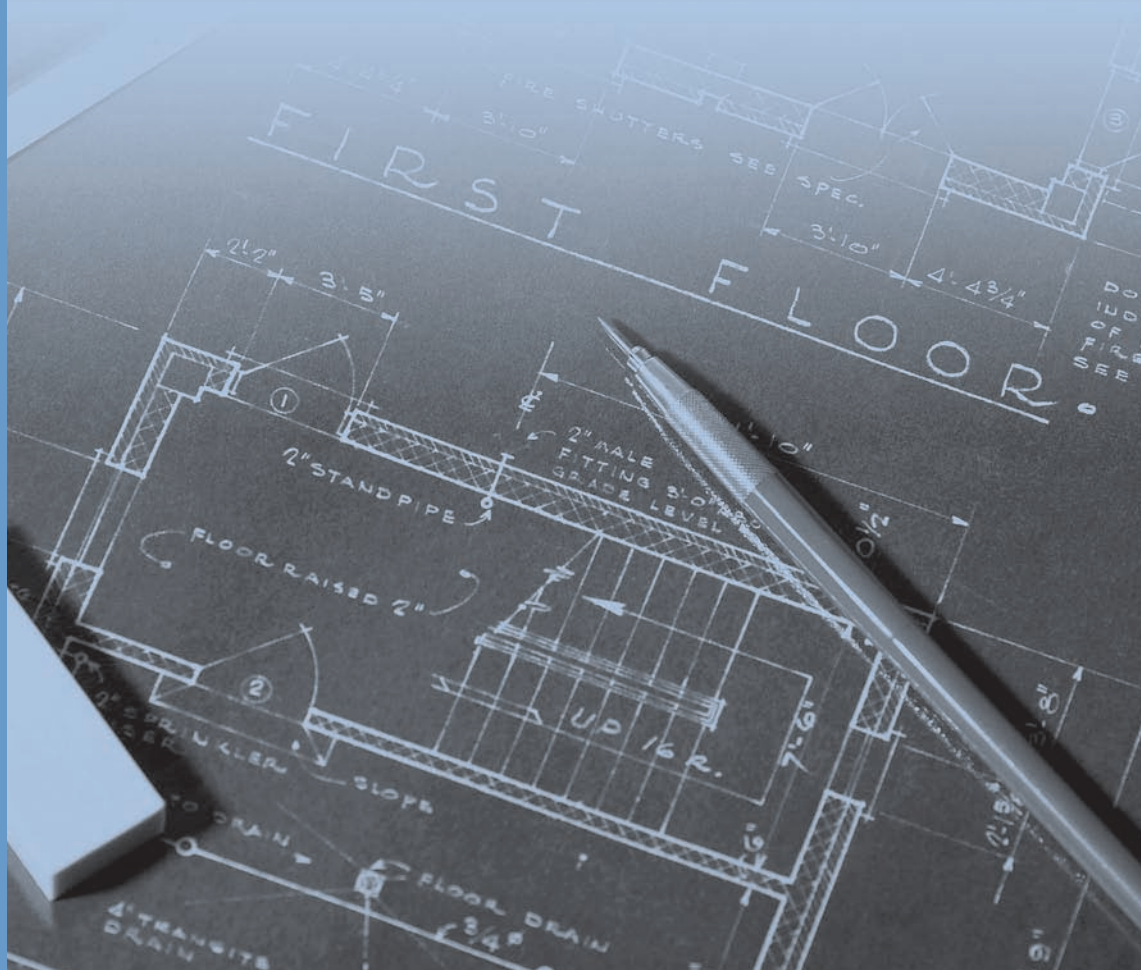
2.9 FINANCIAL MANAGEMENT CONTROLS

The Group recommends that palliative care services in receipt of statutory and/or voluntary funding should be accountable for the way that this funding is spent. Service agreements should be put in place between funding agencies and palliative care services to ensure that there is clear understanding of what is required. Funding should be linked to the attainment of set quality-assurance measures or benchmarks. The Group also believes that it is essential if financial costings are being worked out for palliative care, that both financial and clinical personnel are involved in the process.

CHAPTER 3

ADVISORY GROUP RECOMMENDATIONS:

General Design and Planning Considerations



3.1 DESIGN GUIDELINES FOR SPECIALIST PALLIATIVE CARE SETTINGS

It is an objective of the Advisory Group to facilitate the development of SPC units that create a welcoming and calm environment that deliver the highest standards of SPC for patients and their families. To this end the recommendations of the Design Guidelines for Specialist Palliative Care Settings are endorsed and a number of recommendations are made.

3.2 GENERAL DESIGN AND PLANNING CONSIDERATIONS

3.2.1 Location/Site Selection (Design Guidelines Section 4.1)

The Group agrees with the issues raised in the Design Guidelines for Specialist Palliative Care Settings regarding site selection. It is desirable that future comprehensive SPC units and satellite units where possible are located on the grounds of, or as close as possible to, an acute general hospital with a broad range of diagnostic and treatment facilities. This has a number of potential positive aspects including those outlined below:

- Allows for close functional and operational links between the unit and the acute hospital.
- Makes integration and seamless delivery of services easier to achieve by facilitating interaction with other specialities (e.g. easier for another specialist to visit the patient), and shorter distances for patients to travel for investigations and treatments.
- Increases the level of awareness of acute hospital staff regarding SPC services and enhances and promotes relationships between the two settings of patient care.

Potential negative aspects include:

- Lack of space on existing sites to build new units in surroundings appropriate to SPC (views, gardens etc…).
- Possibility that SPC beds might not be protected for SPC services in times of bed shortages in an acute hospital.

It is understood that the existing SPC inpatient units in Ireland (with the exception of Sligo) are not located on the sites of acute hospitals.

3.2.2 Internal Circulation Spaces (Design Guidelines Section 4.3)

Consideration should be given to providing some beds that are bigger than a standard hospital bed (possibly 1.5x width– would require checking with suppliers regarding the availability of suitable beds with raising/lowering mechanisms etc…) to allow room for a partner/spouse to lie beside the patient. Widths of corridors, doorways and lifts should be designed with this in mind.

3.2.3 External Access (Design Guidelines section 5.1)

Patient bedrooms should have direct outdoor access where possible. The external doorway should be big enough to allow a bed to be wheeled out through it. Space outside on a patio, terrace or balcony should have a surface suitable for wheels and be of adequate size to provide room for a hospital bed, supportive equipment and seating for people accompanying the patient.

3.2.4 Infection Control

It is essential that there are adequate facilities for hand washing on entering all patient bedrooms, in treatment rooms and in other areas as informed by best practice.[17]

3.2.5 Use of Rooms

In designing a SPC unit, it is important to consider that some rooms can serve a variety of purposes. Use of spaces for different functions at different times of the day should be considered. It is felt that the exception to this is the quiet space/contemplation room, which should not double up for other uses.

3.2.6 Mortuary Location

The location of a mortuary and viewing room within a SPC unit needs careful consideration. The location of the mortuary requires consideration of the sensitivities of patients and their families, while at the same time accessibility of the mortuary for transfer of remains from the wards is an important issue. In addition, suitable vehicular access for removal of remains from the unit needs to be provided. It is desirable that discretion is observed when the bodies of deceased patients are being removed from the grounds of the unit.

3.3 STRUCTURAL/FUNCTIONAL CONTENT

3.3.1 Size of Inpatient SPC Unit (Design Guidelines Section 5.1)

The ideal size of a SPC inpatient unit has not been determined. A smaller number of larger units allows for efficiency of scale and an increased range of available services at each unit. However, in this situation there is the potential disadvantage of geographical distance between the SPC unit and some of the areas it serves. The NAC report recommended that there should be at least one SPC inpatient unit (which would be the core essential element of the SPC service) in each former health board region.

The Group agrees with the recommendation of the NAC report on the provision of 8-10 SPC beds/100,000 population. With these recommendations in mind, the Design Guidelines for Specialist Palliative Care Settings calculated that the number of beds in a typical new SPC inpatient unit would be in the order of 2 wards each containing in the region of 18. In recognition of the geographical spread of the population in some regions of the country it was also recommended in the NAC report that SPC satellite units might be necessary. These must function as an extension of the lead SPC unit for the region.

3.3.2 Single Bedrooms with WC and shower facilities (Design Guidelines Para 5.1.1)

It is recommended that provision of all single room accommodation for patients is desirable. The Group gave due consideration to the potential advantages and disadvantages of this arrangement and decided that it serves the best interest of patients.

It will be important for inpatient units to have an increased awareness of, and a structured approach to, addressing the need of patients for social interaction with others.

3.3.3 Artwork Storage Space

In order to facilitate the provision of a pleasant and homely visual environment for patients, it is recommended that a variety of pictures and prints both religious and non-religious should be available for patients to borrow to place in their bedrooms. Storage space for these items should be provided in a convenient location.

3.3.4 Isolation Room (Design Guidelines Section 5.1.3)

In general, isolation rooms can serve two purposes: firstly, they can be used to protect a particularly susceptible patient from exposure to pathogens that might cause serious infec-

tion, and secondly, they can be used for infection control to isolate a patient who carries a specific pathogen. The former situation requires a specially-protected environment and is not a practical option in a SPC setting; patients requiring this protection (e.g. severely neutropaenic patient) should be transferred to a suitable facility. For the purpose of infection control it is currently considered that because of the availability of portable carts (where washing and gowning can take place) that can be left outside a patient's room, it is not necessary to have specifically designed isolation rooms. This provides a more flexible arrangement. Hand washing and universal precautions should be prioritised even where patients are not known to carry infection. Provision needs to be made for storage areas for such carts when not in use.

3.3.5 Nurses Station (Design Guidelines Section 5.1.4)

It should be anticipated that electronic patient records will be the norm in the future (possibly within 5 years). There should be appropriate space and wiring provided for computer equipment in nurses stations. It is estimated that a 14 bed ward will require 5 - 6 computer workstations to be operative.

A reception area should be situated in front of the nurses station in order to facilitate reception functions at ward level. The work area of the nurses station should be separated from this to allow for a suitable work environment and to facilitate maintenance of confidentiality of patients' records.

3.3.6 Religious and Spiritual Needs

It is important to consider that patients can have both religious and/or spiritual needs, and that these may be different. There is an increasing trend in Europe for individuals not to be involved in organised religion, and therefore facilities that are organised entirely around religious activities will not fulfil their wider spiritual needs. Facilities should be provided for both spiritual and religious needs of patients, families and staff. An interdenominational and/or inter-faith chapel or "sacred space" should be provided for the practicing of formal religion and a quiet space or "contemplation room" is needed for the use of all patients. The furnishings should be removable to allow for flexibility of use.

3.3.7 Contemplation Room (Section 5.1.18)

It is recommended that the size of the Contemplation Room should be increased to accommodate 6 – 7 people. The room should be clearly set aside for this function. It should be comfortable and simply furnished without overt religious symbols. Chairs should be comfortable and allow sufficient space for wheelchair use.

3.3.8 Facilities for Patients Wishing to Smoke

If smoking is to be allowed it is recommended that a designated room should be provided for patients (not for visitors) who wish to smoke and that this should have a state-of-the-art ventilation system. It is also recommended that the gardens and grounds of SPC units should have designated smoking areas with adequate litter bins provided.

3.3.9 Facilities for Families and Children Visiting SPC Units

The Group recognises that are security and safety difficulties that need consideration if a designated children's area is to be provided. It is recommended that SPC units should at least be child-friendly with the availability of furniture appropriately sized for children, and possibly the provision of some items for entertainment of children, such as videos, books or toys.

3.3.10 Library & Resource Facilities for Patients and their Families

Patients and their families should have access to reading material and/or videos on a wide range of areas of interest to patients and their families (e.g. information on financial help and services available, support groups, disease, treatment, spiritual care, bereavement etc…).

It would be ideal to have an information centre within an area of the unit. This would be a place where patients, families and the local community (including schools) could have access to information about aspects of their disease process, care, literature etc… that could be facilitated in a supportive way i.e. the centre could be staffed by suitably trained volunteers. The information should be free at the point of delivery. It is recommended that resource/library facilities for staff should be separate to those for patients & their families.

3.3.11 Other Resources and Facilities for Patients

Consideration should be given to the provision of aids and appliances that allow patients with disabilities to maintain independence and to communicate. For people with brain impairment and other neurological disorders such as motor neuron disease, this can prevent them accessing SPC inpatient care as they may have equipment at home that is not available in an inpatient unit. In addition consideration should be given to likely future developments in this area.

3.3.12 Space for Community SPC Services (Design Guidelines Section 5.2)

Consideration of noise levels at busy times is needed in the design of offices for community palliative care services. Quiet private areas are needed for staff making phone calls.

Alternatively, the use of telephone headsets and microphones for dealing with telephone calls for staff working in close proximity with others should be considered. Access to electronic patient records while taking telephone calls is also very important. The team also requires an area where meeting space can be configured easily for meetings, discussion of patients, handover etc…

3.3.13 Spiritual and Pastoral Care (Design Guidelines Section 5.8)

There is need for a vestry/store with provision of a sink to facilitate the preparation for religious ritual and worship. A small safe may be advisable for the safe keeping of silver (chalice etc…) and any monies received during times of worship.

3.3.14 Mortuary (Design Guidelines Section 5.10)

In general in Ireland funeral services do not take place in the mortuary of a SPC Unit. It is not envisaged that this practice will change in the foreseeable future. Usually the body of the deceased person is removed by undertakers for embalming. It is recommended that a viewing area as outlined in the Design Guidelines be incorporated into the design of a mortuary. A small service/ceremony could be held in this area. Permanent religious symbols should be avoided here; it is envisaged that religious symbols could be brought in and out as appropriate to each situation. A suitable secure cupboard should be provided for storage of these items.

3.3.15 Electronic Patient Records and I.T. Developments

Over the next 5 years (approximately) many developments are likely to take place in this area. It is likely that SPC units will have electronic records, and that paperless systems will exist in SPC units. The provision of portable computers (palm tops, lap tops etc…) will be necessary for community palliative care staff. In order to ensure the smooth transition from paper to electronic notes, education and training initiatives will be required for all clinical and administrative staff involved in the recording of patient information.

The recently published National Strategy on Health Information indicates that it is likely that there will be major developments at a national level in the development of electronic health records over a similar time period.[18]

It is also desirable that in the future a patient's SPC record will be accessible to their GP to facilitate information exchange and integration of care. In a similar way, patients should have a means of accessing their own clinical records.

3.3.16 Education and Training Department (Design Guidelines Section 5.11)

Educational Facilities

SPC units should provide suitable facilities for education and training of healthcare professionals. This should be informed by local and regional assessment of educational needs. Facilities should include adequate library space and IT resource rooms. Electronic library resources are becoming increasingly important. In addition, the need for a lecture theatre and rooms for small group workshops should be taken into account. The multidisciplinary nature of education in SPC may necessitate the provision of bigger rooms than might be otherwise anticipated. Adequate office space should be provided for education staff and researchers.

Research and Data Management

Data collection and management is integral to the running of a SPC service. Space and necessary equipment should be provided for individual(s) involved in data collection and data management. Consideration also needs to be given to storage of patients' paper clinical records.

CHAPTER 4

ADVISORY GROUP RECOMMENDATIONS:

Education and Research

4.1 IMPORTANCE OF EDUCATION AND RESEARCH

The Advisory Group believes that education and research are the key components of a high-quality SPC service. These are the tools that allow safety, quality and performance of services to be measured, and areas in need of attention to be highlighted. Education and training of healthcare staff and volunteers involved in delivery of palliative care services is of utmost importance to ensure quality and safety of care provided to patients and their families.

Within a service, ongoing research and audit is essential to identify and monitor areas that need improvement; without this there cannot be satisfactory commitment to continuous improvement. In order to make improvements in the way that people with cancer and other life-limiting conditions die in Ireland over the coming years, the Group believes that it is vital that the areas of education and research receive urgent attention.

4.2 EDUCATION

4.2.1 Education of Healthcare Staff

Most healthcare professionals care for patients with palliative care needs; however many do not receive formal education or training in this area either at undergraduate or post graduate level. The Group believes that education in palliative care is at a critical point in terms of need at this time and has identified a number of priorities:

1. Education of educational leaders, policy makers and managers regarding the needs for education of healthcare professionals in palliative care is vital.

2. Academic departments of palliative care are urgently needed in all faculties of medicine.

3. Basic principles of palliative care should be disseminated to as many healthcare professionals as possible at undergraduate and postgraduate level in all disciplines.

4. Inter-disciplinary training of professionals in palliative care is very important. Palliative care is best provided by a multidisciplinary team approach, and therefore training of professionals from various disciplines together is essential to develop the approach and enhance understanding of what each discipline has to offer. At the same time individual disciplines require their own separate specialist training.

5. Efficient and effective training of staff to work in SPC services is essential to overcome manpower issues and staff shortages.

The following education needs have been identified:

(a) In the immediate term training of new staff who have little or no SPC experience
(b) Medium to long term planning for training of future SPC staff
(c) Ongoing professional development and education for all SPC staff.

Currently most staff enter the services untrained in SPC provision and are trained "on the job". Looking ahead, it is important that systems are developed to provide education at undergraduate and post-graduate levels that will produce heath care professionals who are well trained and who have both practical experience and academic knowledge.

An approach to training and education of staff that are in-post to maintain performance and professional development is outlined in Figure 3. This approach involves understanding required competencies with regard to mission, objectives, policies and plans of the service and individual roles of various staff members. Gaps in competencies need to be continually identified and measures taken to address these through training, mentoring and feedback. This is consistent with the establishment of an annual staff development review process with associated identification of training needs.

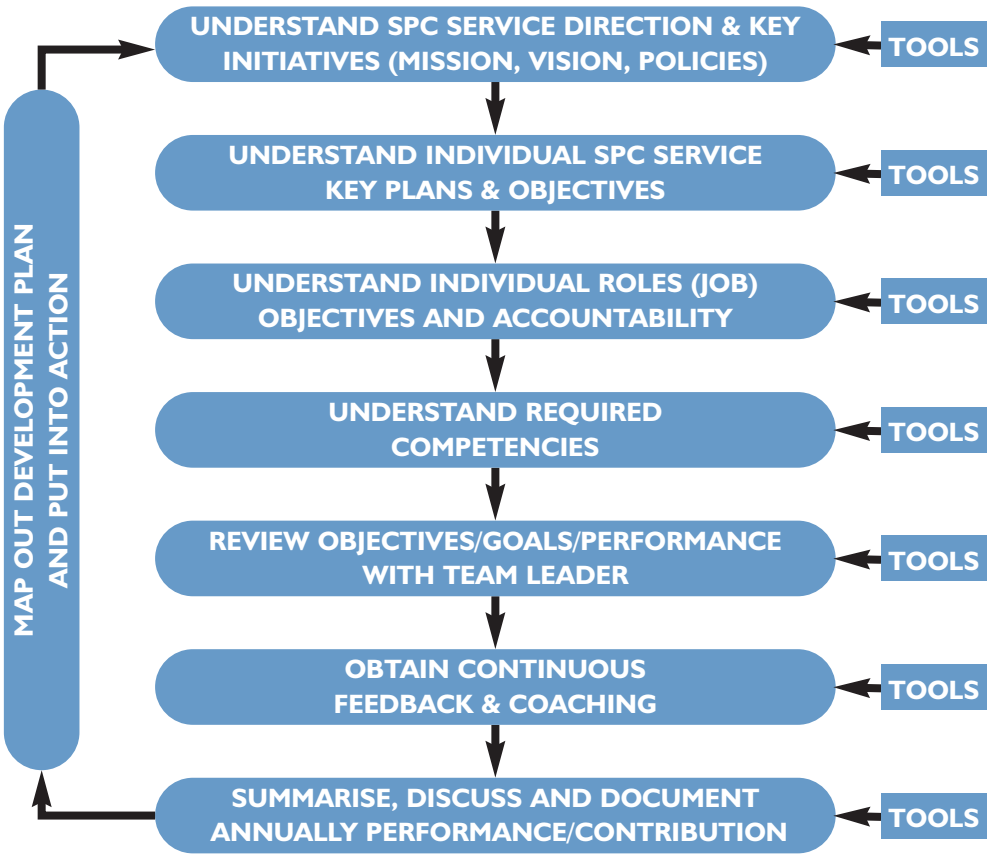


Figure 3: Performance & Professional Development Roadmap

4.2.2 Education of the Public

Education of the public regarding the role of palliative care is a very important step in improving access to services. Many people are not familiar with the term palliative care and there is very commonly a lack of understanding of the services provided by, and the role of, palliative care services, particularly in the areas of symptom control and rehabilitation. This needs to be addressed in order for the maximum number of patients to benefit from palliative care.

4.3 RESEARCH

Research is seen as an investment in the future and if resources are scarce it may not be seen as a priority. However, research is essential to ensure appropriate use of resources and high quality cost effective health care provision. There are two main aspects to palliative care research, both of which are lacking in Ireland:

1. Research into patient care.

For a number of reasons this aspect of palliative care research is underdeveloped on a worldwide level (including lack of funding, inherent difficulties in performing such research, and the historical development of palliative medicine). It is important that the body of scientific knowledge is expanded to ensure further improvements in patient care.

2. Health services research.

In many developed countries this area of palliative medicine is well researched and has been used to inform policy-making and management of resources.

4.3.1 Research Recommendations

The following recommendations are made by the Group:

- Research in palliative care should be seen as a public health priority as it impacts on large numbers of patients and bereaved relatives and friends.
- The development of a culture of research and education/training initiatives, and research fellowships for students and healthcare professionals is of utmost importance in the long-term.

- A core research structure should be put in place to support those committed to research in all four of the new health administrative regions. This structure should provide research expertise (research methodology training, data analysis etc…) and provide funding support for research.

- Professors of palliative medicine should be in a position to oversee and have a strong commitment to the development of palliative care research and should have formal links with a SPC unit.

- It is essential that appointed professors of palliative medicine also have a clinical commitment in palliative medicine

- Academic leadership is essential to ensure focus in palliative care research. It is desirable that Departments of Health Sciences in the various universities appoint professors of palliative medicine who have clinical experience in palliative medicine, research and teaching. The development of independent departments is important. In situations where an individual with all the required experience is not available, it might be necessary to appoint an individual at a less senior level who would link or collaborate with other departments and groups that already have a critical mass, until a suitable person to fill the Chair could be identified.

- Basic data on palliative care activities in Ireland is urgently needed. The proposed Minimum Data Sets for Specialist Palliative Care in Ireland commissioned by the Department of Health and Children are seen as a suitable way to gather this information.

- It is very important that front line clinical staff be supportive of research and understand its importance.

- Charitable organizations and foundations play a very important role in supporting education and research in palliative care.

CHAPTER 5

ADVISORY GROUP RECOMMENDATIONS:

Benchmarks for Best Practice

BENCHMARKS FOR SPECIALIST PALLIATIVE CARE (SPC) SERVICES (APPENDIX A)

The following framework was agreed for drawing up benchmarks for SPC:

1. Benchmarks would be defined in terms of Structure, Process and Outcome.
2. Where applicable, benchmarks would be defined for a baseline level (below which services would be penalised) and for a desired level (level of excellence).
3. These levels would not be static but would be developed over time.
4. The number of benchmarks would be limited and would therefore need careful consideration.
5. Benchmarks are needed for each setting of SPC.
6. The areas in which benchmarks would be defined were chosen.

The following points are emphasised by the Group:

- The benchmarks are a starting point, and will require to be updated regularly in the light of emerging evidence and accepted international best practice. It is suggested that the benchmarks should be reviewed and updated as needed at 2 – 3 yearly intervals in line with other policy revisions, and depending on the speed of developments in the specialty.
- It is important to note that outcomes are not always easy to measure, and in many instances it is easier to measure structure or process.
- The benchmarks have taken into account current SPC practice and provision in Ireland.
- Implementation of these benchmarks needs careful consideration. The recently-established National Council for Specialist Palliative Care would appear to be a suitable body to oversee implementation and updating of these benchmarks.

BENCHMARKS FOR BEST PRACTICE FOR SPECIALIST PALLIATIVE CARE SERVICES

Areas highlighted in bold are suggested areas of measurement for each benchmark

BENCHMARK	STRUCTURE	PROCESS	OUTCOME
SERVICE AVAILABILITY/ACCESS **Cancer:** Baseline Level: 50% of patients who die of cancer access SPC before death. Desired Level: 70% of patients who die of cancer access SPC before death. **Non-Malignant Diseases** The proportion of patients seen by SPC services with non-malignant disease is: Baseline Level: 5% Desired Level: 25% **Out-of-Hours Access to Advice and Information for Non-Specialist Palliative Care Healthcare Professionals** Advice and information is available to non-SPC medical and nursing personnel who are providing palliative care 24 hours a day, 7 days a week.	Integrated data collection system for each SPC service that allows accurate data on patients accessing service to be generated. Staff trained in coding of diagnosis and data collection and entry. Availability of specialist palliative care staff to offer telephone advice and information 24 hours a day 7 days a week. Systems should be put in place to ensure out-of-hours access to clinical data on individual patients.	Keep accurate data on numbers of patients accessing SPC services and the diagnosis for which they are referred. **Generation of statistics on** 1. **Percentage of patients dying of cancer who access SPC before death.** 2. **Numbers of patients accessing SPC who are referred for a non-malignant condition.** **Comparison of data on access by cancer patients of SPC services with Central Statistics Office death certificate statistics on cancer deaths.** Healthcare professionals should be made aware of availability of SPC advice on 24 hour basis. SPC healthcare professionals should respond to requests for advice and information at the earliest possible opportunity.	Patients access SPC services on the basis of need. **Non-SPC healthcare professionals report receiving advice and information they need from SPC staff.**

BENCHMARKS FOR BEST PRACTICE FOR SPECIALIST PALLIATIVE CARE SERVICES

Areas highlighted in bold are suggested areas of measurement for each benchmark

BENCHMARK	STRUCTURE	PROCESS	OUTCOME
STANDARDISED PATIENT ASSESSMENTS **Assessment of:** **Symptoms** A standardised symptom assessment tool is completed for all patients daily in SPC inpatient units, at every home care visit, 3 times weekly in level 2 settings of care and at each day care attendance.	Agreed standardised symptom assessment tool for use throughout the SPC service in all settings of care. Staff are trained in procedure for administration of agreed tools.	Symptoms are assessed using agreed tools The results of assessments are documented in each patient's chart. The results of symptom assessments are used to inform patient care.	**Patients report improved symptom control.**
Cognitive impairment/delirium Cognitive/delirium assessment tool is completed on admission to inpatient unit (SPC or level 2) or first home care visit and weekly (baseline level) thereafter. The desired level is twice weekly in inpatient settings and up to twice weekly in home care if patient is seen more than once a week.	Agreed standardised cognitive/delirium assessment tool for use throughout the SPC service in all settings of care. Staff are trained in procedure for administration of agreed tools.	Cognitive function/delirium is assessed using agreed tools. The results of assessments are documented in each patient's chart. The results of these assessments are used to inform patient care.	**Cognitive impairment/delirium is identified, assessed and managed as appropriate.** **Reversible causes of cognitive impairment/delirium are treated as appropriate in each individual situation.**

BENCHMARKS FOR BEST PRACTICE FOR SPECIALIST PALLIATIVE CARE SERVICES

Areas highlighted in bold are suggested areas of measurement for each benchmark

BENCHMARK	STRUCTURE	PROCESS	OUTCOME
PATIENT AND FAMILY CARE			
Assessment of psychosocial and spiritual needs of patients			
Screening for psychosocial and spiritual needs by a social worker and chaplain/spiritual care provider close to time of first accessing SPC services and at least once per admission to an SPC inpatient unit and home care episode. Screening leads to more in-depth assessment of those where a need is identified.	**Adequate levels of social workers and chaplaincy/spiritual care providers staffing as per NAC recommendations.** **Tools/ Procedures for screening and assessment developed and approved for use.** Staff are trained in the use of screening tools/procedures for assessment.	Agreed procedures for screening and assessment are followed including documentation in the patient's notes. The key points are identified in the patient's journey. Screening leads to more in-depth assessment of those where a need is identified.	Patients state that their psychosocial and spiritual needs are met.
Discharge Planning			
All patients who are being discharged on clinical advice and their family/carers are offered a multidisciplinary discharge planning meeting prior to discharge.	System for organising discharge planning meeting. Collection of contact details for key family members/carers. Structured approach exists to organising and conducting discharge meetings that ensure that key areas in planning patient care are covered.	**A multidisciplinary (at least 2 disciplines) discharge planning meeting takes place with patient and/or family/carers (as appropriate) for all planned discharges.** **The areas covered at such meetings and care plans should be clearly documented in the patient's chart.**	Patients, family members/carers and healthcare professionals have a clear understanding of plans for patient care.

BENCHMARKS FOR BEST PRACTICE FOR SPECIALIST PALLIATIVE CARE SERVICES

Areas highlighted in bold are suggested areas of measurement for each benchmark

BENCHMARK	STRUCTURE	PROCESS	OUTCOME
PATIENT AND FAMILY CARE CONT **Family Psychosocial Support** The psychosocial needs of family members are assessed in a proactive manner during the patient's illness including bereavement risk assessment.	**SPC services have a bereavement support co-ordinator and adequate numbers of social workers to assess psychosocial needs and bereavement risk and offer appropriate support to family members.** There are agreed procedures for assessment of psychosocial needs and bereavement risk.	Psychosocial and bereavement risk assessment is carried out. Family members with psychosocial needs and at risk of complicated bereavement are identified as early as possible. There is provision of appropriate support to individuals and families with psychosocial needs and at risk of complicated bereavement.	Family members report that their psychosocial needs are met. There is satisfactory resolution grief.

BENCHMARKS FOR BEST PRACTICE FOR SPECIALIST PALLIATIVE CARE SERVICES

Areas highlighted in bold are suggested areas of measurement for each benchmark

BENCHMARK	STRUCTURE	PROCESS	OUTCOME
COMMUNICATION			
Healthcare Professionals			
Effective inter-professional communication within multidisciplinary teams, between the providers of SPC in various settings (e.g. inpatient unit, day care, home care, acute hospital, bereavement support) and between SPC service providers and other healthcare professionals involved in patient care.	Facilities should be available and time allowed in work schedules to allow for meetings and communication. Integrated patient record system within a SPC service (e.g. computerised patient record system that can be accessed by SPC staff in all settings of care).	Processes are implemented (e.g. regular multidisciplinary meetings) to ensure effective inter-professional communication within teams. Processes are implemented to ensure seamless movement of patients between the various settings of SPC care (e.g. regular meetings between healthcare professionals in the various settings, shared patient notes, policies and procedures for transferring patients between settings, use of common assessment tools etc). Regular meetings are held between SPC and other key healthcare professionals (e.g. oncologists, radiotherapists) to discuss and feedback information regarding services and individual patients (joint outpatient clinics facilitate communication and integration of patient care).	**SPC team members report satisfactory communication within the team.** **SPC healthcare providers in various settings of care report satisfactory communication within SPC service.** **Other healthcare providers report satisfactory communication with SPC services.**
Patients and Families			
Patients and families have their information needs (e.g. regarding diagnosis, treatment options, available services, etc…) met by SPC services.	SPC healthcare professionals should have training in communication skills and should be aware of the possible range of needs of patients and families for information.	SPC healthcare professionals should regularly assess the information needs of patients and their families and respond to these needs by providing the information themselves or by highlighting the need to more appropriate healthcare professional.	**Patients and families report that their information needs are met.**

BENCHMARKS FOR BEST PRACTICE FOR SPECIALIST PALLIATIVE CARE SERVICES

Areas highlighted in bold are suggested areas of measurement for each benchmark

BENCHMARK	STRUCTURE	PROCESS	OUTCOME
EDUCATIONAL ROLE **SPC Staff**			
Annual development review process is established. This involves the identification of individual staff needs and staff are encouraged to have individual programmes for acquisition of knowledge and skills needed for their respective roles. This staff development review process informs the development and delivery of an educational strategy.	Adequate numbers of education staff to co-ordinate and oversee staff development review process and educational strategy development. A system for identifying appropriate professional development needs on an annual basis exists.	**Implementation of an annual development review process leading to identification of staff training and educational needs.** **Participation by staff in processes to facilitate acquisition of knowledge should be actively encouraged by the service.** **Staff annual development review process should be used to inform educational activities within the SPC service.** **All educational activities should be formally evaluated by the participants, so as to better inform the development and delivery of future training initiatives.**	SPC staff acquire the knowledge and skills needed to provide high quality specialist palliative care to patients and their families.
Education of Non-Specialist Palliative Care Healthcare Professionals			
Provision of appropriate education and training (based on need) of non-specialist palliative care healthcare professionals e.g. running sessions/courses on communication, how to discuss commencement of opioid, how to rotate opioids etc…	Adequate numbers of education staff to design appropriate educational sessions or courses. A system for identifying educational and training needs of non-specialist PC professionals delivering PC (e.g. PHN, GP, junior doctors, oncology staff etc…).	Opportunistic education of non-SPC staff on-the-spot in clinical situations. Running of accessible relevant educational and training sessions and courses as informed by needs of non-specialist healthcare professionals. All educational activities should be formally evaluated by the participants, so as to better inform the development and delivery of future training initiatives.	**Non-SPC healthcare professionals report palliative care education/training needs are met.**

BENCHMARKS FOR BEST PRACTICE FOR SPECIALIST PALLIATIVE CARE SERVICES

Areas highlighted in bold are suggested areas of measurement for each benchmark

BENCHMARK	STRUCTURE	PROCESS	OUTCOME
RESEARCH ROLE			
Organisation has an awareness and commitment to keep up-to-date with and take part in research (at local, national or international level) Staff understand the importance and value of research.	There is a structured approach to dissemination of research findings (e.g. regular journal clubs, updates etc…). Staff are trained/educated on the importance and value of research, its uses and interpretation, and issues of recruitment, consent, data collection and ethics.	Evidence from research is used to inform practice and implement change. The organisation participates in research projects.	**The organisation participates in research projects and such projects are presented and published at national and/or international level.**
CONTINUING QUALITY IMPROVEMENT			
Activity Reports			
Generation of reports on activities e.g. length of stay, place of death, % discharges, where discharged to etc…	Database capable of generating activity reports. Person/persons to oversee the entering of data and generation of reports.	Staff training on data collection. Structured collection of necessary data for activity reports. Generation of activity reports and audits. Use of activities reports to examine and inform service provision by the SPC service.	There is continuous quality improvement in the service and staff are aware of the importance of this.
Audit Programme			
The use of an active clinical audit programme that includes evaluation of the views of patients and carers. Information generated from this is disseminated throughout the organisation/SPC service.	There is agreement on areas to be audited with possible use of a validated palliative care audit tool. Staff member(s) are identified to oversee the audit programme. There is a structured approach to collection of necessary information for audit.	Staff receive training and education on collection of necessary information and the value of audit. Use of findings of the audit programme to inform patient care and service provision.	There is continuous quality improvement in the service and staff are aware of the importance of this.

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